
AIDS Community Demonstration Projects for HIV Prevention Among Hard-to-Reach Groups

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Synopsis

The AIDS Community Demonstration Projects are multicenter prevention projects directing community-based interventions to members of hard-to-reach groups at risk of infection from human immunodeficiency virus (HIV), which causes acquired immunodeficiency syndrome (AIDS). The projects are supported by the Centers for Disease Control (CDC). Interventions are de-

rived from theories of behavior change and have as their goal reducing HIV and other sexually transmitted diseases in the communities.

The current objectives, intentionally narrow to improve the project's specificity and clarity, are to increase the use of condoms in sexual activity and the use of bleach to clean injecting drug equipment. Additional objectives may be added. The impact of the interventions is seen in increases in the use of HIV counseling and testing services, decreases in all or specific sexual and drug-use risk behaviors, and requests for related social and public health services.

A quasi-experimental research design is being used to evaluate the projects. Multiple evaluation measures are used, including a street-based interview with randomly identified respondents in both intervention and control communities. Success in facilitating HIV and AIDS risk reduction is being measured using a model of behavior change describing stages of change. Upon successful completion of these projects in 1994, CDC may be able to offer models of effective, feasible, and easy-to-monitor HIV and AIDS prevention activities to State and local health departments and community-based organizations.

THE AIDS COMMUNITY DEMONSTRATION PROJECTS are community-level intervention trials designed to decrease the frequency of behaviors that place people at risk of infection from the human immunodeficiency virus (HIV), which causes acquired immunodeficiency syndrome (AIDS).

The projects have been funded by the Centers for Disease Control (CDC) since 1986 and include sites in Albany, NY; Dallas, TX; Denver, CO; Long Beach, CA; and Seattle, WA. CDC staff, including behavioral scientists and administrative and support personnel, monitor progress and trouble-shoot problems. The projects' onsite personnel provide considerable technical assistance to each other, sharing experiences, successes, and failures in regular joint meetings and consultations.

Since October 1989, the projects have been operating as multicenter studies, following a joint

protocol devised through the collaboration of staff members at all sites and CDC and of consultants. The complex multistep protocol has required research staff training and careful coordination of activities.

History

In 1986, CDC funded four public health departments (Seattle-King County, Dallas County, Denver County, and New York State) to conduct intervention activities with the group that was at greatest risk of HIV infection in those communities, homosexual and bisexual men. At that time, debate flourished regarding the value of HIV testing and counseling and the behavior changes to be advocated.

Practically no interventions were available for persons at risk outside of the epidemic epicenters, San Francisco and New York. Little consensus

existed on which of the intervention approaches would be best to follow. In the light of these considerations, most projects opted to offer HIV antibody counseling and testing to those men who requested it. The intervention and the services offered differed from site to site but usually involved one-on-one counseling coupled with offering HIV antibody testing.

In 1987, funds were awarded to new projects (Chicago, Long Beach, and New York City). Existing projects were expanded to include groups recognized as at risk of HIV infection, injecting drug users who share injection equipment, their female sex partners, male and female prostitutes, and adolescents in high-risk situations. For the most part, interventions for these persons centered on providing, in clinical or other institutional settings, information about HIV infection. Some projects provided HIV-antibody testing and counseling as well.

Evaluation of interventions directed toward homosexual men in the early stage of the AIDS Community Demonstration Projects centered on recruiting and following cohorts of homosexual men. We coordinated the efforts of researchers at the sites in developing a core questionnaire for evaluation; individual sites added specific questions. A followup core questionnaire was developed. HIV prevention services were made available to homosexual men in health department clinics, and men who used those services were asked to participate in the evaluation study by completing a self-administered questionnaire prior to counseling and testing for HIV antibodies. The participants were asked to return in 6 months to retest those who had tested negative, as well as those who had tested seropositive and requested verification. Participants who completed the first followup questionnaire received additional counseling to reinforce the behavior change message and were asked to return again in 6 months. To date, more than 5,000 men have participated in the evaluation study. Results have been presented in numerous meetings and are being prepared for publication (1-6).

A similar evaluation strategy is being used to assess the effect of HIV antibody testing and counseling on injecting drug users recruited from the street rather than treatment centers. They are offered participation in a followup study and are asked to complete an interviewer-administered questionnaire. Aggressive followup is used to locate those who participate initially but fail to return. To date, 800 injecting drug users have participated in the study in New York City. Results of this

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research have been presented (7) and published (8). A summary paper is in preparation.

New Approach

The early phase of the AIDS Community Demonstration Projects offered interventions in clinical or storefront settings to those who believed themselves in need of HIV prevention services. The interventions were largely one-on-one counseling and were evaluated by following those who agreed to participate in longitudinal cohorts. These projects provided important information, but were plagued by such shortcomings as a person having to perceive a need for help in changing their

behavior and to come to a clinical setting. The exact nature of the interventions provided differed in response to the person's needs and were difficult to evaluate. We decided that the early interventions and their associated cohort studies were not suitable for the new groups that we needed to address.

In reorienting the AIDS Community Demonstration Projects, we selected five groups, men who have sex with men but who do not identify themselves as homosexual or gay, injecting drug users not in treatment programs, women who are or may be the sex partners of men in these two groups, prostitutes, and high-risk adolescents, especially those outside the supervision of home or school. Because these groups had characteristically avoided health department-sponsored (and largely clinic-based) interventions, we encouraged the use of community-based, rather than clinic-based, interventions. We studied as models community-based, small (as opposed to mass) media campaigns designed to lower the risk of cardiovascular disease (9, 10) or cancer (11, 12).

In 1989, we began developing a protocol, which included important new features, to guide the activities of the new multicenter projects. The first feature was a period of formative evaluation (13) to develop a suitable understanding of the groups of interest. The second feature was a theoretically-driven intervention plan that used community volunteers and carefully chosen materials for small media to accomplish its goals. The third was a research design that called for repeated cross-sectional measurement within intervention and control communities and the establishment of multiple baseline measurements prior to intervention.

Formative Evaluation Process

As an initial step to understanding the subject groups, the researchers undertook a period of ethnographic research (14). Following training, the project leaders at each site began so-called systems interviews with health department professionals and AIDS researchers. Examples of the information gathered through systems interviews are

- estimated size of the risk group,
- subgroups within the risk group,
- languages predominately spoken by members of the risk group,
- structure of the community in which members of the risk group are found,
- HIV prevention and other health resources available to members of the risk group,

- migration patterns (if any) of the risk group or subgroup members,
- access points for risk group members,
- degree of personal safety in the areas where risk groups members are located, and
- the opinions of those interviewed on (a) predisposing factors that increase the risk for risk group members to acquire or transmit HIV, (b) the group's perception of risk for HIV infection, (c) actual HIV risk behaviors of the group's members, and (d) the group's perceived and actual barriers to HIV risk reduction.

Next, health department non-AIDS researchers who had met members of the groups in question were interviewed, followed by other nonhealth department professionals, such as police, judicial system workers, program directors in shelters, and people in charitable organizations.

The next step in this process was to observe people in the groups. Using a standard protocol, project workers went to sites identified in the systems interviews and observed unobtrusively. This observation was a critical first step in understanding group members' lives from the perspective of how it is viewed and interpreted by the people themselves, and not as it is explained by those outside the groups (15). Gaining this perspective can lead to an understanding not only of the behaviors people engage in but of their motivations (15).

The next step was identifying and interviewing the gatekeepers, those who often act as arbiters between the groups under study and the rest of the world. In some cases, the gatekeepers were themselves members of the groups; in other cases, they were outside the groups. The information sought was the same as in the systems interviews, but the perspective of those interviewed was different.

The final step was interviews with members of the groups themselves. Both indepth, one-on-one interviews and focus group interviews were conducted. We attempted to gain the insider's perspective and focused on the types of risk-taking, the advantages and disadvantages of reducing risk through safer sexual and drug-using practices, what the respondents thought might be useful ways to help people like themselves avoid risk-taking, and typical patterns of daily life. This last point was important in helping us discover where, when, and how to contact people during the day to deliver the intervention. From this extensive qualitative data, we gained useful insights and the results of our activity are being compiled for inclusion in a book describing the projects' current activities.

Examples of information gathered through key participant interviews and focus group interviews with risk group members are

- types of risk behaviors currently practiced,
- intentions to practice safe behaviors,
- perceived advantages of adopting safe behaviors,
- perceived disadvantages of adopting safe behaviors,
- perceived barriers to the adoption of safe behaviors,
- perceived facilitators of the adoption of safe behaviors,
- use and existence of support systems (for example, friends and family),
- perception of risk for acquiring or transmitting HIV,
- daily activity patterns, and
- types and specific media used.

Theoretical Premise

Having gained useful insights into the risk behaviors and the motives for the behaviors of the group members, we continued to question how to change those behaviors. Our goal was to facilitate behavior change to decrease the likelihood of HIV transmission. The behaviors included increasing the use of condoms in sexual activity and decreasing the use of shared drug injection equipment as well as increasing use of bleach by injecting drug users who cannot be convinced to stop sharing equipment. Interventions designed to achieve these goals must be easy to implement, feasible, quantifiable, and adaptable to new information and diverse environments. These constraints argued for using interventions based on theories of behavior change and using an evaluation plan that allowed measurement of change in theoretically important factors related to the subject behaviors.

We studied the primarily cognitive theories of behavior change, consulted with experts, and identified three well-established theories from which other theories are derived: the Health Belief Model (16), the Theory of Reasoned Action (17, 18), and the Social Learning Theory (19, 20).

We listed the elements contained in each model and compared them. Although the list was long, the separate concepts represented were few. From this exercise, we identified a short list of theoretical elements that contained most of the information in these models. Our study focused not on hypotheses derived from one model but rather those derived from the commonalities of all the models (21).

'Because the role models and the volunteers are, for the most part, like the subject population, the intervention should serve to make people feel capable of changing their behavior (that is, increase their perceived self-efficacy) and believe that the expected standards of behavior have changed in their communities (that is, change their perception of community norms).

We used a final model, Stages of Behavior Change (22-27), which describes behavior change as a series of steps. The stages are labeled *precontemplation* (no intention to change one's behavior), *contemplation* (long-range intentions to change), *ready-for-action* (short-range intentions to change), *action* (attempts to change), *maintenance* (long-term consistent behavior change), and *relapse* (which can restart the process or simply bring the new behavior to a halt).

Interventions are most effective when they can be tailored to fit the needs of the subject who is at a particular stage in the change process. This model has been used to describe a variety of health-related behaviors (22-27), but only recently to describe sexual behavior and HIV infection (28). We are using this model for two purposes, to guide the intervention effort and to identify intermediate indicators of success prior to the adoption of long-term consistent risk avoidance. The utility of the model that guides intervention efforts deserves examination (its use in evaluation will be explained subsequently).

Certain cognitive elements should be more important at some stages of change than they are at others. For example, perception of risk (drawn from the Health Belief Model) will be more important in the earliest stage of the change process, precontemplation, than in the later stages (contemplation, ready-for-action, action, and maintenance). Similarly, self-efficacy (from the Social Learning Theory) is likely to be most important at the ready-for-action and action stages. With this set of hypothetical relationships as a guide, the content of the intervention messages should be adjusted to match the stages of change of most of the group members. Since variation in stage of change exists, the relative importance of the cognitive elements in

the intervention messages will be adjusted. Stages of change and related cognitive areas are

Stage of change: precontemplative

Primary objectives: think about risk reduction and norms and assess risks to self and others

Cognitive area: outcome expectations and norms, perceived risk

Stage of change: contemplative

Primary objectives: evaluate outcomes, make risk reduction a priority, form intention to change, commit to change, acquire skills

Cognitive area: outcome expectations and norms, value and priority, intention, self-efficacy

Stage of change: ready for action

Primary objectives: form intention to change soon, evaluate outcomes, acquire skills

Cognitive area: self-efficacy, intention, outcome expectations

Stage of change: action

Primary objectives: perform behavior, perform behavior in various situations, perform behavior consistently

Cognitive area: outcome expectations and norms, self-efficacy

Stage of change: maintenance

Primary objectives: perform behavior in various situations consistently during a significant period

Cognitive area: norms, self-efficacy

Stage of change: relapse

Primary objectives: reevaluate outcomes, reestablish priority, reform intention, recommit to change

Cognitive area: outcome expectations and norms, value or priority, intention, self-efficacy

Interventions

According to Social Learning Theory (19, 20), learning new behaviors takes place through modeling the behaviors of others, particularly those perceived as attractive or important. People need not model their behavior after people they know personally; models encountered through the media can stimulate acquisition of new skills and attitudes (29, 30). However, initiating new behaviors requires both cues from the environment, cues that are most effectively relayed through interpersonal communication, and reinforcement (31).

Reinforcement can be intentionally provided in

intervention efforts, through the development of community organizations, for example, or it may take place through informal networks (11, 32-33).

The content of the interventions in the AIDS Community Demonstration Projects is based on the theoretical elements outlined, while the form of those interventions derives directly from the principles of Social Learning Theory. In these interventions, small media (as opposed to mass media) materials, such as brochures, posters, and audio and video tapes, are prepared. The materials contain role model stories of people dealing with the problems of behavior change to avoid HIV. The stories are authentic, told in the language of the story tellers, who are men and women from the streets of the communities, and the stories are packaged attractively. We choose stories on the basis of our hypotheses outlined previously and on measurements of the stages of change in the community.

For example, if evaluation showed that most of the injecting drug users were in the precontemplative stage, the role model stories would feature a person who was realizing the personal risk that sharing needles had posed and who was developing concerns about HIV infection. The stories offer credible and feasible role models from whom group members can learn the new behaviors necessary to protect themselves from HIV.

The second feature of our intervention efforts is the distribution of these materials. In each community, networks of volunteers are recruited that may include some of those selected for behavior change. They may be local shopkeepers or people recognized as not being members of the groups, but as connections between that group and the rest of the community. The materials are delivered to the audience through the volunteers either actively (going door-to-door or out on the streets) or passively (when people come into a merchant's store).

This volunteer network serves the important functions of directing people's attention to the materials, providing cues to attempt behavior change, and reinforcing changes that do take place. Because the role models and the volunteers are, for the most part, like the subject population, the intervention should serve to make people feel capable of changing their behavior (that is, increase their perceived self-efficacy) and make them believe that the expected standards of behavior have changed in their communities (that is, change their perception of community norms). Through steady application of this intervention effort, we hope to

induce or accelerate behavior change in the community as it moves toward consistent HIV risk reduction and the development of new community norms that support HIV prevention.

Evaluation

We have found shortcomings in using longitudinal studies in which subjects are compared with themselves at a previous time, for evaluation purposes. Recruitment bias, large numbers lost to followup, and the Hawthorne effect (34) may complicate interpretation. We decided to use repeated cross-sectional surveys of people on the streets as the major outcome evaluation tool. These surveys take place in the subject neighborhoods and in carefully selected control neighborhoods where no intervention is yet planned by these projects.

The survey instruments are designed to be used on the streets with randomly selected persons in treatment and control areas. The instrument eliminates those who admit to no recent risk-taking behaviors. For those who qualify for inclusion in the survey, the instrument elicits information about their sexual and drug-use behaviors, their level of information and concern about AIDS and HIV and their intentions to change in the distant and near future. This questionnaire is brief and does not contain all the information needed to guide the intervention effort or to evaluate the outcome. A longer instrument that contains more detail on the cognitive processes of behavior change and the previous experiences of the respondents is being administered to a randomly drawn sample of the respondents from the first survey. Interviewing on the streets takes place every other month. Three waves of baseline data have been collected in each of the neighborhoods.

The major evaluation research instruments have been developed using qualitative data from the formative evaluation efforts and quantitative information from pretests and measurement studies. These instruments allow us to assess a person's stages of change mentioned previously and thus to measure the central tendency of the audience on stages of change. With this information, we can adjust our intervention content according to our theoretical premise. While our goal is eventually to move the entire community toward long-term, consistent behavior change, the interventions are viewed as successful if we can detect movement through the stages of change toward that goal.

Other evaluation information is being collected.

Unobtrusive measures (35) are being used to supplement the self-report measures. The difference in numbers of discarded bleach bottles and condom wrappers in treatment and control areas (determined by periodic intentional counts) and STD rates and requests for HIV counseling and testing between the treatment and control areas are being assessed. Impact of the interventions is being measured by studying the recognition and retention of the information contained in the intervention materials. Process evaluation is measuring the extent to which intervention is taking place as planned. The data collection systems for these evaluation components are designed to provide rapid feedback on the progress of the intervention effort and to allow quick problem identification and correction. When complete, these data should provide sufficient detail to allow us to measure the overall success of the community-level effort to change HIV risk behaviors.

Conclusion

The current AIDS Community Demonstration Projects are conducting research on community-level primary prevention of HIV for groups that are hard to reach through standard interventions and, thus, still at high risk for HIV. With a complex set of steps, the goal of these projects is to translate this research into a package of interventions that can be implemented by other State and local health departments. The State and local health departments that are currently conducting this research effort can serve as models for others in their ability to conduct effective primary prevention for HIV outside the usual health department settings and with difficult-to-reach groups.

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